

Autism Minority Outreach Initiative

A Living Beyond Autism Project

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1-in-68 U.S. children is diagnosed with autism, a neurological disorder. African-American and Hispanic children are diagnosed later in life compared to white children, according to national research. Proper diagnosis, early intervention, and lifelong treatment are critical to support a person living with autism. This project aims to help raise awareness about autism within minority communities throughout Ohio.



Living Beyond Autism



Ohio Developmental
Disabilities Council

Mission Statements



Living Beyond Autism

Living Beyond Autism (LBA) promotes early intervention and outreach programs for unrepresented and underserved populations impacted by autism. We advocate for awareness, early intervention, and research and support.

Ohio Developmental Disabilities Council

The mission of the Ohio Developmental Disabilities Council is to create change that improves independence, productivity and inclusion for people with developmental disabilities and their families in community life.

Ohio Center for Autism and Low Incidence

The Ohio Center for Autism and Low Incidence (OCALI) serves families, educators, and professionals working with students with autism and low-incidence disabilities, including autism spectrum disorder, multiple disabilities, orthopedic impairments, other health impairments, and traumatic brain injuries.

Based on a respect for individuals with autism and low incidence disabilities and our belief in their right, need, and desire to achieve their full potential, OCALI's mission is to build state- and system-wide capacity to improve their outcomes through leadership, training and professional development, technical assistance, collaboration, and technology.

Further, we believe that families, as well as professionals, play a critical role in promoting the highest possible achievement of each child. To that end, we see connection and partnership with families as vital to the success of each individual at school and in the community.

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Welcome family and friends

I remember when my second son, Grant, turned 2-years-old, demonstrating all the developmental traits that delight a father – the babbling that gives way to short sentences and singing the alphabet song and the curiosity of wanting to grab everything within his tiny reach. As parents, it seemed as though our Grant was well on his way to be like his older brother, a typically developing child allowing you to dream ahead to kindergarten and tee ball and Disney World trips.

But then, as quickly as it takes a light to dim when a switch is turned off, Grant began showing startling signs of regression. Suddenly, no more short sentences, just one-word utterances. No more singing, in fact, he could no longer recite the alphabet at all. His pre-school teachers noticed it, too. They noticed a change in his behavior for the worse and greater challenges with academic retention. They immediately suggested it might be attention deficit disorder, delayed speech development or some other ailment. As parents, we had his pediatrician evaluate Grant for all of the above. But other than an obvious case of delayed speech that seemed to grow worse by the moment, there was no firm diagnosis for what was failing Grant. And with no proper diagnosis there could be no proper plan of treatment.

It would take us 24 long months before we would finally get a proper diagnosis for Grant. He has autism. 'What is autism?' I can remember wondering and asking. I would soon learn. And I also learned there was no cure for autism. And what scared me most was that my best hope for helping my son learn to live with this neurological disorder was to get him intervention services as early in life as possible. In my mind, we had already lost more than two years of potential treatment while we struggled to find out what ailed Grant. And even with the diagnosis, it would take nearly a year before we could find a treatment – still not convinced it was the right treatment plan – to help Grant.

Today Grant is a teenager still learning to live with his condition with the loving support of his family and friends. Given that early intervention is key, it is my wish that no parent will ever have to wait two crucial years before learning their child has autism. Living Beyond Autism hopes this report and resources will serve as tools of awareness and education for our communities, especially those living in underrepresented minority areas where an autism diagnosis is most often missed. There is hope. Together, we can teach those around us about autism and help those living with this condition live fulfilling lives.

Kind Regards,



Reginald Fields
Living Beyond Autism, co-founder

Overview

In 2014, the U.S. Centers for Disease Control and Prevention released updated figures on the prevalence of autism in America. The report concluded that 1-in-68 children has been diagnosed with autism spectrum disorder (ASD), an alarming figure that reveals a rapid increase. The current rate is roughly 30% higher than the estimate for 2008 (1-in-88), roughly 60% higher than the estimate for 2006 (1 in 110), and roughly 120% higher than the estimates for 2002 and 2000 (1 in 150) (10 Things to Know About New Autism Data, 2014).

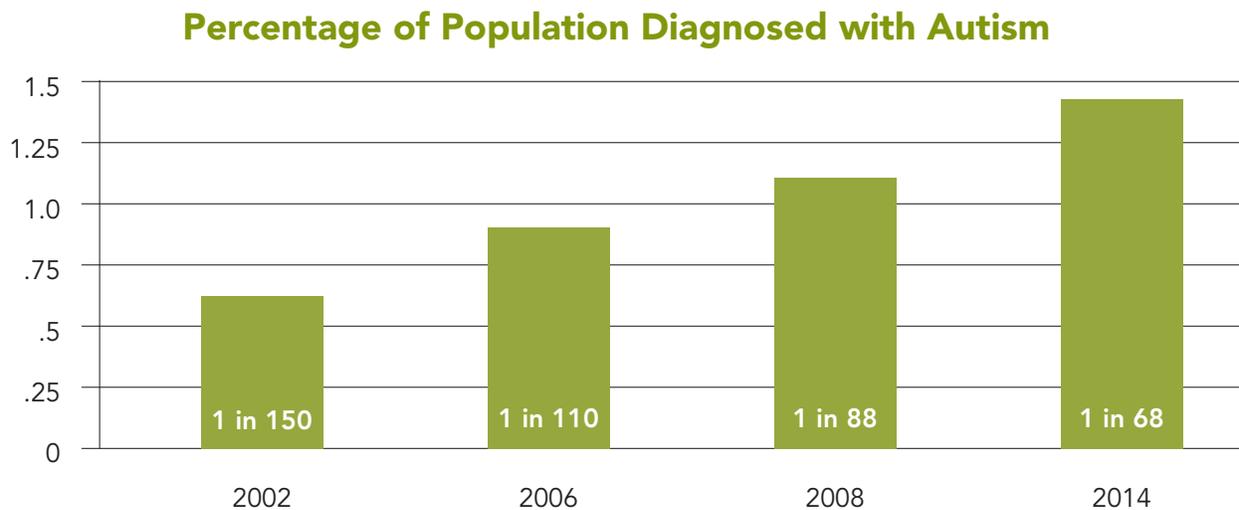


Figure 1: Rate of autism among U.S. children is rapidly increasing, according to the U.S. Centers for Disease Control and Prevention.

Living Beyond Autism (LBA) is a non-profit organization based in Ohio that is dedicated to raising autism awareness within minority and under-served communities and advocating for more accessible services for people and families impacted by autism.

In 2012, LBA, with support from the Ohio Center for Autism and Low Incidence (OCALI) and the Ohio Developmental Disabilities Council (ODDC), launched a project intended to increase autism awareness within minority communities. The Autism Minority Outreach Initiative (AMOI) features the thoughts and comments of 21 African-American parents who participated in two, 90-minute focus groups during which they were asked to share their experiences from when they first began to observe concerns about their child's development, to receiving a diagnosis of autism, to later adjusting their lives since learning of the diagnosis.



21 African American parents participated in focus groups to share their experiences with their children with autism.

The project consists of this written report which outlines the overall project and places it in perspective of the challenges for Central Ohio, the state of Ohio, the Midwest region and the country as a whole. The written report will be accompanied by a companion video-documentary that features several of the parents who participated in the focus groups. Aside from their participation in the focus group discussions, parents volunteered to separately expound on thoughts they shared in the group discussion, offering personal, detailed accounts of their experiences in raising a minority child who has autism. It is these personal accounts that are the mainframe of the video, a strong supporting storytelling piece that helps further illustrate the challenges faced by parents of children with autism. The same video is being produced in two separate lengths – approximately 10 minutes and approximately four minutes – so that it can be flexibly used for presentations.

Providing information through the broadcast media is also planned to support this outreach effort. Neilson Media research indicated that in 2013 there were a total of 590,750 African American TV homes and 126,580 Hispanic TV homes across Ohio. To touch these communities, the project also features the production of Public Service Announcements (PSAs) developed to target each of these communities. A 10 second and 30 second PSA was developed for each group. Requests to air these PSAs will be sent to Ohio's 55 broadcast stations representing 11 TV markets. This campaign also includes the broadcast of a radio interview with Reggie Fields, a parent of a son with Autism Spectrum Disorder and the Co-Chairman of the OCALI Advisory Board, as spokesperson for early identification and diagnosis. In addition, OCALI will issue a press release through the PR Newswire for placement on broadcast websites.

Through our partnerships with OCALI and ODDC, this project is highly anticipated and has been promoted or will be promoted at conferences, workshops, programs that draw interested statewide and national stakeholders – parents, educators, healthcare providers, researchers, advocates and government officials. The AMOI project and related materials supplied by OCALI have been distributed at 68 Federally Qualified Health Centers throughout Ohio. Materials will also be distributed this spring at the Ohio Early Care and Education Conference in Columbus, the largest such annual conference in Ohio serving early education and child care programs across the state. Help Me Grow, an early childhood program maintained through the Ohio Department of Health, and a collaborative partner of OCALI has similarly offered to disseminate and help promote the AMOI project. And OCALI is a sponsor of the Autism Diagnosis and Education project, an initiative aimed at training physicians to look for early signs to properly diagnose autism and to launch early intervention autism treatment programs for families. In addition, OCALI will promote the AMOI project as part of its work with this initiative to assure that

physicians are aware that a racial gap in the diagnosis of autism for white and minority children is clearly evident and can be closed with greater awareness.

Goals

The aim of this project is to use the information that has been researched and assembled to highlight autism awareness within minority and under-served communities throughout Ohio. This report will serve as a significant community service tool as the need for this type of information within the targeted audiences is long overdue and crucial to the future quality of life of individuals with autism and for their families. An increase in awareness could lead to a greater opportunity for individuals impacted by autism to lead prosperous, independent lives and could also lessen long-term reliance on government-assistance programs, which presents an added benefit for Ohio taxpayers and those who may not have a direct, personal connection to autism.

This project – the written report, videos, PSAs and educational materials – will be presented and/or made available at state education and/or healthcare conferences between January 2014 and December 2015. The project will be featured throughout healthcare and early childhood and early education programs in all 88 Ohio counties during this same time period. The project, and its key points of awareness, outreach and resources, will reach minority families across Ohio during this 24 month period. The project is hailed as the premier effort within Ohio dedicated to raising awareness about autism specifically to minority families, including African-Americans, Hispanics, Asians and first generation African descent families.

Significance of This Project

In 2014 the U.S. Centers for Disease Control and Prevention (CDC) released the results of a new study that concluded that 1-in-68 American children has now been diagnosed with some form of autism. This represents an alarming growth rate within a short time period. The previous rate was 1-in-110 in 2008 and 1-in-150 based on data from 2000. That means the prevalence of autism diagnoses nearly doubled in just a dozen years. But deep within those numbers is a more troubling tale for minority families. The rate of autism in white children is 1-in-68 while the rate is 1-in-81 for African-American children (CDC, 2014).

But that only scratches the surface of the trouble when it comes to assessing how autism disproportionately impacts minority families as compared to white families. There have been a number of studies over the past decade that have tried to determine whether there are significant differences among racial groups in regards to the age at which a child is diagnosed with autism. Nearly every report has concluded that indeed a significant gap does exist.

Average Age at Time of Autism Diagnosis

White children

6.3
years old

African American Children

7.9
years old

On average, white children received the autism disorder diagnosis at 6.3 years of age, compared to 7.9 years for black children (Mandell, Listerud, Levy, & Pinto-Martin, 2002). Another report concluded that African-American children with autism were diagnosed an average of 1.4 years later than white children (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). And the more recent CDC report indicates that the average age for diagnosis of autism is lowering for all children and among all racial groups; however, the gap in diagnosis remains with African-American children still being diagnosed about 18 months later than white children. Much the same is true for Hispanic children who are also diagnosed at an older age when compared to white children (Palmer et. al, 2010).

Why is this important? Because there is no cure for autism. There are various therapy treatment services that in best case scenarios can help a child with autism learn to manage their disorder well enough to be included in school classrooms alongside typically-developing students which gives that person with autism an increased chance to someday live an adult life with minimal or no assistance. However, these treatments are proven to be most effective when they are first applied early in a child's life – preferably at or before 24 months or age.

Since medical professionals are now able to detect and diagnose autism as early as 18-to -24 months, that means appropriate services can be applied earlier in the child's life. Conversely, children who are diagnosed much later in life, for example, well after they have started their schooling – which is typical for minority children who have been diagnosed with autism – the prospects and odds of these children being able to participate in traditional classrooms and someday lead independent lives with minimal or no government and medical assistance is sharply diminished. As a result, African-American children may require longer and more intensive intervention (Gourdine, Baffour, & Teasley, 2011). This puts into clear perspective why it is so critical for a child with autism to receive an accurate diagnosis early in life.

This, of course, begs yet another question: Why are minority children with autism typically diagnosed later in their lives than white children? This is not an easy question to address because the answers can vary widely and blame could rest with various groups – parents, physicians, teachers or government leaders who restrict resources that could help. But there are two responses that appear to resonate most with the minority parents who participated in this LBA project: either parents were unaware of autism and thus did not know that they should long ago have had their child screened for autism or medical professionals and teachers were unprepared to properly make a diagnosis of autism. Instead, minority children with autism are often first misdiagnosed as having other, more treatable and less alarming disorders, such as, speech delay or attention deficit/hyperactivity disorder (ADHD). It should be noted that the symptoms of autism could take on the characteristic of a speech delay or ADHD.

Parental Viewpoint

Of the 21 parents who participated in the LBA focus groups, 10 said that they believe their child's autism condition was initially misdiagnosed as something less significant. The parents generally reported that while they noticed a change in their child's development, healthcare professionals consistently did not connect these signs as indicators of autism spectrum disorder, which delayed a diagnosis and the start of appropriate treatment. In fact, one mother said that her pediatrician told her that her son was merely "spoiled" because the parents and an older sibling appeared too often to speak for the boy and do things for him. Even among the ten parents who said that they believe their child was properly diagnosed, they note that the diagnosis only came after the parents had educated themselves about autism and specifically requested that their child be screened for autism.

"My doctors said he isn't talking because he is a boy," said Gwen Harshaw, who has a teenage son with autism. But the Harshaws knew that there was something more serious impacting their son. Eventually, they learned about autism and then asked their medical professionals to specifically assess their son for this neurological disorder. "We discovered everything on our own," Harshaw recalls.

Like the Harshaws, a proper diagnosis for many minority families comes only after the child has started school, meaning many valuable early years of treatment were missed. A pediatrician had not recommended an autism screening prior to these parents requesting one for their child. Many of these parents lament not knowing more about autism and faulted their child's pediatrician or teachers for not alerting them to this possibility earlier in their child's life. "My son's teacher said he is mentally retarded and he should be in an institution," Brenda Knox recalled. Knox' son is not mentally retarded. He was later diagnosed with autism. "He can't talk, he can't defend himself."

The majority of the participants reported that it was more than two years from the time they first suspected concerns about their child and the point at which their child was diagnosed with autism. One mother said it took seven years. And more troubling, given that it is crucial for treatment of autism to begin early in life, nine of the 21 participating parents said their child was not diagnosed with autism until they were a teenager.

Another troubling aspect of a delayed diagnosis is that negative behaviors can begin to set in for a person who is living with autism but not receiving treatment or the treatment did not start soon enough. "My son is becoming more and more frustrated with his lack of communication," said Michelle Hooper. The Hooper family is trying to raise money to purchase a laptop-like device that would help their son to communicate his thoughts. "I have to figure out how to get the money and resources to get the expensive tools to help my son communicate."

And many families who begin to feel as though they are running out of options say they have increasingly turned to their faith. "I put my faith in God," said Gena Moore, who has a daughter with autism. "It was hard. It was emotional. I didn't know how to face this. But I'm not going to give up on my child."

The experience of parents in this project appears to align with what national studies have depicted. Differences in diagnostic patterns by ethnicity suggest possible variations in parents' descriptions of symptoms, clinician interpretations and expectations, or symptom presentation, a national report concluded (Mandell, Ittenbach, Levy, & Pinto-Martin, 2007). This is not to say that white children are not

also too often failed by a professional's misdiagnosis or by parents who might lack awareness of autism. Ethnicity and socio-economic status do not consistently influence the prevalence of autism and although there appears to be no ethnic bias in the tools or manner of screening for autism, the same cannot be definitively stated for the doctors and medical professionals who must make the decision on whether to suspect autism as an ailment and actually apply the screening (Begeer, Bouk, Boussaid, Terwogt, & Koot, 2009).

It has been speculated that professionals screen for autism spectrum disorder less often in children from minority than majority groups (Mandell et al., 2002). This, in turn, means that minority children with autism are less likely to gain timely access to appropriate services. While socio-economic conditions may not fully explain the racial gap in diagnosis, access to healthcare could be a factor. The frequency of how often a child sees a doctor, regardless of family income, could be a factor. The low rate of autism for Hispanic children in Western Texas, for example, could be explained by the fact that Hispanic children when compared to white children are less likely to have health insurance and three times more likely to live below the poverty line and are twice more likely to lack access to medical care (Palmer et. al.).

Current research indicates that there are multiple reasons for the later diagnosis of autism spectrum disorder in children of minority families. Whether the delay in diagnosis is the result of the lack of awareness of ASD characteristics on the part of parents, the families' lack of access to medical care, or the lack of knowledge on the part of medical professionals serving these families, the solution is clear. We must make this issue a topic of concern and engage families and service providers in discussions about its causes and the strategies we might use to address them. This report will serve as the first step in beginning this discussion for Ohio.

Recommendations

- 1** Educate the medical and service provider communities about the age gap in autism identification among minority (African American and Hispanic) children and white children.
- 2** Increase the level of awareness among the minority community of autism spectrum disorder and its signs so parents can alert their child's medical professionals when they suspect a problem.
- 3** Inform families in the minority communities about the benefits of early identification and early intervention.
- 4** Empower families to trust their perceptions and seek additional support if they have questions about their child's development. Inform families about resources they can access for an early identification if their healthcare professional is not responsive.
- 5** Utilize the strong network of faith communities as a mechanism to disseminate information to African American and Hispanic families.

References

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Resources

Ohio Center for Autism and Low Incidence (OCALI)

470 Glenmont Avenue
Columbus, OH 43214
(866) 886-2254
www.ocali.org

Ohio Developmental Disabilities Council

899 E. Broad Street, Suite 203
Columbus, Ohio 43205
(614) 466-5205 or (800) 766-7426
www.ddc.ohio.gov

Ohio Department of Developmental Disabilities

30 E. Broad Street, 12th Floor
Columbus, OH 43215-3434
(800) 617-6733
www.dodd.ohio.gov

Columbus Speech and Hearing Center

510 East North Broadway Street
Columbus, OH 43214
(614) 263-5151

Nationwide Children's Hospital Development Center

700 Children's Drive
Columbus, Ohio 43205
(614) 722-2000

Nationwide Children's Hospital Center for Autism Spectrum Disorders

187 Schrock Road
Westerville, OH 43081
(614) 355-8315
www.nationwidechildrens.org/autism

Ohio Department of Education

25 South Front Street
Columbus, Ohio 43215-4183
(877) 644-6338
Contact for Autism Scholarship Program
Office of Nonpublic Educational Options
(614) 466-5743
Toll-free: (877) 644-6338
www.autismscholarship@education.ohio.gov

Columbus State College

Disability Services
Autistic Self Help Advocacy Group
550 East Spring Street
Columbus, OH 43215
(614) 287-5353
mlatimer@autisticadvocacy.org

Autism Speaks

(888) 288-4762
www.autismspeaks.org

Autism Society of Ohio

470 Glenmont Ave.
Columbus, OH 43214
Telephone: (614) 487-4726
www.autismohio.org

Other Resources

OCALI Services and Supports Database

For additional services available in your area, check the Services and Supports Database at the OCALI website. Choose the appropriate age range for the individual and select the appropriate service category. You will be asked to input your zip code to identify the service providers closest to you.

Check out the OCALI Services and Supports Database at: familyservices.ocali.org

OCALI Lending Library

Books and DVDs can be checked out at no cost by all Ohio citizens. After you have registered with the OCALI Library by downloading and mailing in the registration form, you will receive a client code number. This will allow you to order resources online and have them shipped directly to you by UPS at no cost. A return label will be sent to you after 3 weeks to allow you to return resources by UPS, also at no cost.

Check out the OCALI Lending Library at: www.ocali.org/project/lending_library